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The “We” in the “Me”:¹ Solidarity and Healthcare in the Era of Personalized Medicine

Abstract

This paper challenges a key tacit assumption underpinning legal and ethical instruments in healthcare, namely that people are ideally bounded, independent, and often also strategically rational individuals. Such an understanding of personhood has been criticized within feminist and other critical scholarship as being unfit to capture the deeply relational nature of human beings. In the field of medicine, however, it also causes tangible problems. I propose that a solidarity-based perspective entails a relational approach and as such helps to formulate new solutions to complex ethical and regulatory questions, ranging from caring for people at the end of their lives to improving policies for organ donation and better governance of health data. It also underscores the importance of universal healthcare. Although a solidarity-based perspective does not require health to be seen as an individually enforceable right, it

¹ I would like to draw attention to Mette Nordahl Svendsen’s project that carries the reverse title:

‘MeInWe – Personalized Medicine in the Welfare State’ (meinwe.ku.dk). Our two projects, each in its own way, seek to bridge the opposition that Donna Dickenson described in her book *Me Medicine vs.*

We Medicine: Reclaiming Biotechnology for the Common Good (Dickenson 2013).

does influence our understanding of individual rights: It draws attention to how their meanings are shaped by shared social practices. I conclude by arguing that, in light of current pressures for medicine to become more personalized, using a relational understanding of personhood to shape policies and practices is a much needed endeavour.

Keywords: Personalized Medicine, Precision medicine, relational autonomy, solidarity, end-of-life, organ donation, data governance, right to health

Introduction

There is currently a lot of excitement, and also considerable concern, about personalized medicine (e.g. Dickenson 2013; Vollmann et al. 2015). In its broadest definition personalized medicine seeks to match diagnosis and treatment more closely to the specific characteristics of individual patients. Variations of this idea are also referred to as stratified medicine, and as “precision medicine.” The latter term is used by some authors to mark a departure from the narrow focus on genetic and genomic information that personalized medicine had in the immediate aftermath of the Human Genome Project (Hedgecoe 2004; Juengst et al. 2016). Current iterations of personalized or “precision” medicine hold that people’s genetic makeup, their lifestyles and other environmental factors vary to such a degree that the analysis of symptoms, medical prognoses, and treatments should also be specific to each individual. In its extreme form, personalized medicine implies a radical individualization of medicine in the sense that every person is seen to represent a unique case of health or disease (NAS 2011; Prainsack 2015).

This idea of personalization goes hand in hand with a growing rhetoric around patient autonomy, shared decision-making, and “participatory medicine” (Keogh 2015; Prainsack 2017). The alliance between these discourses is not a coincidence: For personalized medicine to be realized, people need to invest data, time, and effort. In other words, personalized medicine requires considerable amounts of “patient work” (Strauss et al. 1982, 1997 [1985]). Patient empowerment, although often called for with the best intentions, at times serves as a discursive tool to sweep the more onerous, painful or costly sides of patient work under a shiny carpet. This is the case especially with data-driven and high-tech visions of personalized medicine that require patients to collect data and submit themselves to increasing levels of surveillance, yet without allowing them to bring to the decision making process what is valuable and meaningful to them (Prainsack 2017). If we want to prevent such a version of personalized medicine from becoming dominant we need to appropriate the concept and fill it with new meaning. Such a “new” meaning can draw upon many values and practices that have been around for a long time: It should include the acknowledgement of the importance of “thick descriptions”—that is, narrative information that includes more than a simplified range of predetermined parameters—alongside quantified, digital data. It should also include an emphasis on personal relations alongside machine learning and automation, and the acknowledgement and harnessing of ambivalence amidst our quest for precision and clarity. Giving such “old” practices and values more room in contemporary understandings of personalized medicine is not only a timely project in the face of the fast proliferation of “precision medicine” programmes in the world; it is also an opportunity to revisit our understanding of the person in medicine more broadly.

Regulatory and ethical instruments that guide medical practice and research today are heavily influenced by the idea of persons as bounded, ideally independent (“autonomous”), and regularly also strategically rational individuals (Prainsack 2014; Dove et al. 2017). In medical practice and research more broadly, this understanding creates tangible problems, as I will argue below. In connection with personalized medicine, it poses the risk that personalization will contribute to a greater individualization of medicine—in the form of more responsibilities and duties being devolved to patients, an even greater shift to consumer-driven healthcare, or the decreasing willingness of people to pay into systems that could support others who they deem undeserving. I believe that this should and can be avoided.

Building upon the work of scholars who have criticized the “tyranny of autonomy” in Western medicine (Foster 2009; see also O’Neill 2003; Manson & O’Neill 2007; Fox & Swazey 2008), my own critique focuses on an understanding of autonomy that regards people as independent, *atomistic* individuals. Following feminist and other critical scholarship (e.g. Mackenzie & Stoljar 2000) I argue that conceptualizing persons as bounded, ideally independent, and—due to the close connection between Western individualism and strategic rationality—regularly self-interested individuals is not only flawed, but has been an obstacle to ethical progress in the field. Using the concept of solidarity, I will suggest ways to overcome an unproductive focus on atomistic autonomy. This step is necessary to work towards a kind of personalized medicine that does not force us to choose between “Me Medicine” and “We Medicine” (Dickenson 2013). Another implication of a solidarity-based approach is a focus on healthcare that is affordable and accessible for all. This latter argument does

not entail a claim of the existence of an *individual* right to health: Our solidarity-based approach is agnostic regarding whether an individual right to health does or should exist. As an approach that understands humans as relational beings whose wellbeing is dependent on the wellbeing of others, it posits that societies have a responsibility to meet the fundamental needs of everybody as well as they can. Such a perspective also affects how we understand individual rights in the sense that their meaning is always shaped by collective responsibilities and shared social practice.

The person as a rational, bounded entity

The autonomous individual has been the central bearer of agency in Western thought (e.g. C. Taylor 1985; Douzinas 2000; Richardson 2007; Battersby 2007; Siedentop 2014). In other regions of the world, and in other times throughout human history, selfhood and human action have been conceived in a more “communal” sense (e.g. Tsai 2001; Bird-David 2004). This is the case, for example, when people’s actions are considered to be determined by the role that a person fulfills as part of her community, instead of being construed as the result of reasoned and strategically rational individual choices (see also Strathern 1988; Siedentop 2014).

This Western notion of the autonomous individual is rooted in the notion of self-ownership, whose many nuances are too manifold to do justice to in a short overview. The following characteristics, however, are central to self-ownership: Self-awareness, free will (independent from, and unmanipulated by, others), and the capacity to formulate life plans (see also Christman 2015). Some understandings of self-ownership are strongly influenced by Immanuel Kant’s idea that human beings—as rational agents in the way just described—have an inherent dignity and must not be

treated merely as means to an end (see also Cohen 1995). Other understandings of autonomy *qua* self-ownership draw upon a more *strategic*, instrumental understanding of rationality whose early beginnings are often traced back to John Locke's work on property (1689) as well as to his, and Thomas Hobbes' (1651), conception of the "state of nature." As is well known, the state of nature is shorthand for the (fictitious) circumstances under which humans lived before politically organized societies emerged.¹ Hobbes saw social institutions in the state of nature as reducible to individual choices, an idea that Charlotte Epstein called the "traditional founding myth for the rational actor" (Epstein 2013: 289; see also Murdoch 1992; Neal 1988). Individual choices needed to aim at self-preservation, and these choices in turn became seen as the building bricks of institutions. The focus on the rational and often also strategically reasoned action of individuals (typically individual *men*) also served to distinguish supposedly highly civilized from allegedly "primitive" or pagan societies: While the latter were considered to consist of parochial groups that each worshipped their own gods, the former were seen to comprise *individuals* coming together around shared beliefs and goals (Macfarlane 1978: 52). Larry Siedentop goes as far as arguing that by positing that every human being was created in God's image and could have a personal relationship with God, Christianity gave birth both to the idea of the individual and to the idea of free will: In contrast to antiquity, where the worship of family ancestors and the acceptance of one's role within the extended family were the keys to immortality, Christianity gave each person responsibility for the resurrection of his or her own soul (Siedentop 2014). In this reading it was the free will of each individual that linked rationality to the goal of self-preservation. Rationality was not merely a capacity that elevated human beings

above animals—and male citizens over women and slaves, who were seen as led mostly by their sensations and sentiments; it became instrumental to self-preservation.

The rational choice paradigm has strongly influenced understandings of personhood in virtually every domain in Western Societies. Because of its promise to make human practice measurable and predictable, it has been particularly attractive also for scientific disciplines such as economics, law, or political science. Its foothold in disciplines that are less reliant on quantification has been weaker. At a time when other fields had adopted the rational actor paradigm, most philosophers had alternative views of personhood, including Hannah Arendt, Martin Heidegger, Hans-Georg Gadamer, Martin Buber, and Emmanuel Levinas (for an overview see Sharon 2014). Feminist scholars, including proponents of the care ethics approach, and other critics of modern liberal political philosophy, explicitly emphasized that the human ability to reason is developed through relationships with others (e.g. Gilligan 1982; Strathern 1988; Butler 1990; Meyers 1994). For authors in these traditions, human relationality is a precondition for subjectivity, not the other way around (C. Taylor 1985: Chapter 7; C. Taylor 1989; Mackenzie & Stoljar 2000). We are who we are because we relate to others.

As is well known, postmodern theory in the 1960s and 1970s—spanning many disciplines and traditions within the humanities and social sciences—dealt an additional blow to the idea of the self as a fixed, coherent and bounded entity. Nevertheless, in many areas of public life, the idea of the strategically rational, self-interested individual has remained the core unit that structures social and political space. This view is so deeply engrained in our social and political institutions and

legal frameworks (including our understanding of human rights) that it is difficult to conceive of an alternative.

Exemplified by three cases, the next sections of this paper will argue that the deep-rooted idea of the bounded, autonomous, and strategically rational individual is ill-suited for regulation, practice, and research in medicine. The first case shows how such an understanding of personhood creates problems in end-of-life care—especially when these settings are culturally diverse. If we seek to include in our understanding of medicine factors outside of clinical metrics and indicators, especially those that subjectively matter to patients, then the improvement of protocols and practices of decision making at the end of life are an important goal.

The second case argues that a clear separation between “altruistic” organ donation and non-altruistic donation is unhelpful in theory and in practice, and prevents us from developing better solutions for the organ shortage. Although organ donation may not seem directly related to personalised medicine, the lesson that it teaches us—namely that overcoming the binary opposition between self-interest and care for others can lead to better policies—is particularly relevant for personalized medicine. It can help to avoid the idea that personalization becomes synonymous with a kind of individualization that destroys social bonds and solidarity. Although the latter can be the outcome if personalization is taken as an excuse to devolve onerous responsibilities from the collective level to individuals, personalization can also entail that people affirm and help each other by helping themselves, and vice versa.

The third case shows how the governance of health data also suffers from the problem that persons are understood as bounded atomistic individuals. A consequence of this

is the lack of recognition of the needs and interests of secondary data subjects—that is, people who could be harmed by the use of data that stem not from them but from somebody else who is associated with them. Another unfortunate result of an atomistic understanding of personhood is the dearth of efforts to strengthen not only individual, but also collective, public ownership and oversight to counterbalance the increasing power of private corporate actors in the health data domain—an area that lies at the core of personalized medicine. In a later section of this paper I will argue that solidarity can help to alleviate some of the problems that a focus on self-interested independent individuals has brought to the field of medicine. It is one that also reflects on how we understand the human in human rights.

The comfort of kin?ⁱⁱ Decision making at the end of life

The principle of informed consent has been one of the ethical foundations of Western medical practice since the second half of the 20th century. Understandings of the meaning and role of informed consent are far from uniform. They range from treating informed consent as an individual right to express one's personal autonomy, to conceptualizations that see consent as a part of an ethical dialogue, or as a permission given to others to do things to us that they would otherwise not be allowed to do. The latter types of conceptualizations see consent as only one of the many ways of expressing autonomy (Manson & O'Neill 2007).

At the same time as consent has been lauded as an important step to help avoid deception and coercion, it has attracted a lot of criticism. Such criticism has included, for example, that it is impossible for consent to be fully informed and specific; that it runs the risk of becoming a formulaic stand-in for ethical dialogue and deliberation;

and that it does not automatically increase autonomy in a meaningful way (e.g. O'Neill 2003; Manson & O'Neill 2007; Koenig 2014). Over the decades, this critique has fuelled improvements and new practical solutions around consent (e.g. O'Neill 2003; Manson & O'Neill 2007; Beyleveld & Brownsword 2007; Kaye et al. 2011; Dove et al. 2011; Prainsack & Buyx 2013). The point I wish to make here, however, relates to another, less discussed aspect of informed consent, namely the assumption that it expresses a decision that has normally been made by *one* person. There are, of course, mechanisms and protocols in place for persons incapable of giving consent, because they may be too young, too frail, unconscious, or in another situation that compromises their capacity to make an autonomous decision. The assumption remains, however, that the default rule is that only one person needs to consent to treatment that is done on her body (see also Dove et al. 2017).

In an impactful article published in 1995, medical anthropologists Barbara Koenig and Jan Gates-Williams drew upon ethnographic fieldwork with patients at the end of their lives. They described situations where pain was inflicted on patients, family members, or medical professionals because existing guidelines and protocols clashed with social and cultural norms. As the authors argued, “it is useful to bear in mind that in many Asian societies, ideas about ‘selfhood’ vary from the western ideal of an autonomous individual” (Koenig & Gates-Williams 1995: 247; see also Sariola & Simpson 2011). This does not suggest that there is a dichotomy between community-based understandings of selfhood in the East and individualistic understandings in the West, which would be far too simplistic: The meaning of “culture” unfolds to its full extent only in considering the person’s history and environment. The point here is that an understanding of personhood that sees people as shaped by their relations with

their human, natural and artifactual environments, and as always connected to them, is in tension with most of the ethical and legal instruments that govern Western biomedicine.

The notion of “relational autonomy” (Balkan 1966; Mackenzie & Stoljar 2000) can be helpful here. Already in 1990, Jennifer Nedelsky argued that legal scholarship and practice needed “a new conception of the tension between the collective and the individual, for which the boundary is not an apt metaphor” (Nedelsky 1990: 162). This is the case because “[w]hat actually makes human autonomy possible is not isolation but relationship” (1990: 169). Such an approach is strongly influenced by feminist scholarship, which—in the words of legal scholar Margaret Jane Radin—is generally marked by a “receptiveness to connectedness, to the recognition that human life is impossible without nurturing from those who care for us when we are helpless and dependent” (Radin 1996: 72; see also Powers & Faden 2006, Nedelsky 1990; 2011; Zeiler 2007).

In the second half of the 2000s, bioethicists introduced the notion of relational autonomy into public health ethics (e.g. Baylis et al. 2008), and it has since been used for wider areas of medical ethics and decision making (e.g. Laurie 2014). There have been, however, surprisingly few attempts to translate the rich and nuanced critique of an individualistic understanding of autonomy into new approaches and tools for decision making in the medical domain (Dove et al. 2017). I argue that this is the case because much of the critique within medical ethics has focused autonomy instead of re-thinking the individual.

If we employed an alternative understanding of persons as connected selves (Widdows 2013)—underpinned by a notion of relational autonomy, instead of atomistic, individualistic autonomy—this would require policies and protocols that acknowledge the social nature of decision-making processes (see also Priaulx & Wrigley 2013). Decision-making processes at the end of life specifically are social in at least two respects: first, in the sense that many patients’ decisions on where and how they would like to die are shaped by conversations with family, friends, or clinicians; second, in the sense that considerations for other people literally “make up” part of who we are, especially at the end of our lives (Strathern 1988; Hacking 2006). The increasing uptake of models of shared decision making in palliative medicine and other areas of clinical care goes a long way in accommodating this social nature of decision making (Charles et al. 1997). But it does not go far enough. Taking relational autonomy seriously in end-of-life healthcare also means that we need to make much stronger use of metrics for the assessment and reimbursement of healthcare that go beyond clinical outcomes (see also NHS Scotland 2016). Such a focus on factors that matter “subjectively” to patients would also help to make healthcare at this stage of life more personal in the deep sense of the word (see also Budin-Ljøsne & Harris 2016).

Altruism vs. self-interest: A false distinction in organ donation by living donors

As noted above, the conceptualization of persons as bounded and ideally independent individuals is closely related to the notion of strategic and instrumental rationality. Rational action is aimed at maximizing our own benefit. This understanding, in turn, rests on the idea that it is possible to distinguish clearly between self-interest and care for others. In the field of live organ donation this distinction is one of the fundamental

categories guiding legislation and policy: It separates purely “altruistic” donations from others that are motivated by other reasons, including allegedly selfish ones. This assumption causes problems because the feelings, motivations and practices of people typically do not fit into these categories. It could be argued that this misfit between the legal and institutional categories on the one hand, and practice on the other, is not unique to live organ donation, or even medicine more broadly. The classification work done by written rules always needs to be amended by the practical judgement of people “enacting” these rules (Wagenaar 2004). What makes the misfit in this field so troubling, however, is that if it cannot be bypassed effectively, it affects decisions over life and death.

Informal ways of dealing with the misfit between legal categories and social practices in the field of live organ donation have emerged in many countries. Marie-Andrée Jacob’s (2012) ethnographic study on live organ donation in Israel is one of the few that provides insights into the creation of such informal practices. Jacob carried out interviews, and observed the work of patients, health care providers, administrators, and transplant “brokers.” In the past, Israeli regulations on live organ donations had drawn international media attention for accepting forms of organ procurement that were seen as morally problematic in other countries. Furthermore, cases of organ trafficking especially have made it into the news (e.g. Brimelow 2009).

Orthodox Judaism defines death as the cessation of aerobic activity. For this reason, many members of strictly orthodox communities do not accept brain death as a valid criterion of death, which makes many cadaveric organ transplantations impossible. As a result, the rate of organ donations in Israel is very low compared to Western

countries. In 2015, Israel's cadaveric organ donation rate was at nine per million people, compared to 40 per million in Spain, 29 per million in the United States, and 26 in France.ⁱⁱⁱ The shortage of available cadaveric organs for donation has had two main consequences: before organ trafficking was outlawed in 2008, it had led to the flourishing of alternative supply channels. And it has led to living donations—mostly kidneys—composing the bulk of organ donations in Israel (Boas 2009; Transplant Procurement Management 2010).

For living donations, Israeli regulations differentiate between donations within close family, within remote family, friends, and “unrelated donations” (Jacob 2012: 35). Potential donations within the “unrelated donations” group are referred to as “altruistic donations” (Jacob 2012: 37), and a separate kind of committee is set up to process applications for donations from this group. To establish whether donations are truly altruistic, donors and applicants are interviewed separately by the committee, which is explicitly tasked with filtering out donors who secretly receive financial compensation from the prospective recipient.

Already at the outset of Jacob's very rich study it becomes apparent that the reality of “matching organs with patients,” as Jacob calls it, does not fit into the categories with which the system operates. Perhaps the most pronounced example for how even the most “altruistic” motivations always have a self-interested component is the story of Sandra, a Christian American who decided to donate a kidney to an Israeli Jewish recipient, Yitzhak—and the Israeli hospital committee approved this donation as genuinely altruistic. Sandra did not know Yitzhak when she decided to donate a kidney to him; she learned about him in a newsletter that a Jewish friend had given to

her for her to learn more about Jewish religion. When she read the item on an Israeli man with kidney disease who was in desperate need of a donor, Sandra said she experienced a moment of divine inspiration: “I was at home alone; I was praying, and as I was, God interrupted me, and said: ‘I want you to give your kidney’” (quoted from Jacob 2012: 39). This decision, Sandra said, was a source of profound happiness for her, a way of enacting her faith. The donation saved Yitzhak’s life, but it helped her too. Against this backdrop, drawing a clear line between purely altruistic and self-serving motivations does not seem to be possible. This is supported by another finding from Jacob’s study: She observed how unrelated donors—those suspected of purely pecuniary motivations—are regularly encouraged by brokers to make up shared stories to qualify for an altruistic donation. But in this process of faking closeness, they often develop emotional connections to each other. The result is that, also in this group, donations are sometimes not only motivated by “selfish” reasons (in addition to the fact that donors who seek payment often do this out of concern for children or other family members, which is not a purely selfish motivation either). As I will argue below, the best way to accommodate the simultaneity of self-interested and other-regarding practice in the field of organ donation would be to give up the category of altruistic donations altogether and move to a system that includes everybody as a potential donor and as a potential recipient—as long as they do not opt out.

Health data governance: Protecting secondary data subjects in data-driven personalized medicine

How we understand personhood has important implications for the way we envisage and enact personalized medicine. As noted, while personalized medicine has long

been understood as pertaining to the matching of drugs or treatment to genetic characteristics of patients, the notion has started to broaden; it now includes wider ranges of information and data reflecting individual characteristics of patients. Most visions to realize personalized medicine revolve around the idea that data representing various aspects of people's health, diseases, and lives, often in digital and computable form, will be integrated in order to tailor healthcare more precisely to the characteristics and needs of individual patients (ESF 2012).

Drawing on Graeme Laurie's work (2001), Mark Taylor (2012) criticizes current legal frameworks applicable to the governance of genetic data used for research, suggesting that these frameworks wrongly presume "personal data" relate only to the person from whom the data originate. "Secondary" data subjects, i.e. people who are not the originators of the physical source of genetic data but with whom the information can be associated (e.g. family members), currently enjoy far fewer privacy protections than primary data subjects. More equality between primary and secondary data subjects, Taylor argues, would represent an important step towards better data protection frameworks in the context of genetic research, including better ways to respond to discrimination: Because many biological data pertain to characteristics that are shared between biological relatives, the same set of genetic data can disclose information on, or contribute to the identification of, more than one individual.^{iv}

The value of Taylor's argument is not limited to genetic data alone; it applies to a much wider range of health data. Information about my mother's hypertension, my neighbour's mental health problems, and my friend's breast cancer, for example, all

disclose information that can be used to make probabilistic inferences about their biological relatives and family members. Health information is social in at least two ways: it pertains not only to one person, and in that we make sense of it in connection and in collaboration with others. This renders richer and relational understandings of the “personal” an important goal.

The practice of solidarity

Alena Buyx and I have used the notion of solidarity to address challenges in bioethics and healthcare by focusing on *relations and interactions* between people, instead of treating social reality as reducible to the actions of independent individuals. We understand solidarity not as an abstract value or a sentiment, but first and foremost as practice (Cook & Wagenaar 2012). In its most bare-bones form, solidaristic practices are those by which people or groups express their willingness to accept “costs” (understood widely as any kind of financial, emotional, social, or other contributions) to assist others with whom they recognize similarity in a relevant respect. Solidarity at the “lowest” level, namely between individuals (tier 1 solidarity), can become so common that it becomes a social norm within a group or community (tier 2 solidarity). If group-based solidarity solidifies further and coagulates into contractual or legal norms, then we speak of “tier 3” solidarity. This latter level of solidarity is characteristic, for example, of European welfare states (Prainsack & Buyx 2017). Solidarity—in contrast to altruism, for example—is a deeply relational practice: it requires others with whom we recognize similarity and who are at the receiving end of our solidaristic practice. It is also based on a view of persons as relational beings whose subjectivities and needs are partly shaped by our human, natural and artifactual environments.

As the brief cases of decision making at the end of life, of live organ donations, and of health data governance have shown, the assumption that social and political space is composed of autonomous, independent and strategically rational individuals is problematic, and creates tangible issues in the practice and research of medicine. A more relational understanding of people and their practices can help here. Acknowledging the social nature not only of decision making but of people's needs and interest in a more formal way would thus be a step in the right direction. At first sight this may seem difficult to realize: There are important practical and legal reasons for the dominance of individual consent, for example, and there are currently few, if any, feasible alternatives. Experiments with community consent have proven to be too complex to operationalize (Reardon 2005; see also Widdows 2013), and they run the risk of prioritizing the decisions of powerful actors, such as village elders, powerful patriarchs, over the interests of weaker ones, such as children, stigmatized groups, and often also women. The same applies to family consent. Here, attempts to overcome the limitations of atomistic individual autonomy run into the very problem that legal and ethical instruments focusing on individual autonomy were initially destined to solve, namely that people can be harmed by the actions of others. This is especially pertinent in cases where procedures are physically invasive or otherwise impactful on the body and mind of a specific person. In such cases the default solution must be that the person most directly affected needs to give their consent. This cannot be devolved to other people in her social environment (except in cases where the person cannot give valid consent on her own).

As argued in connection with healthcare at the end of life, what institutions *can* do, however, is to acknowledge explicitly that the process leading up to the recording of informed consent is a social process rather than a situation of isolated decision making based on rational reasoning of individuals. They can treat collective decision making as a normal and valuable human practice, and not as something that reflects a deviation from standard protocols. The adoption of shared decision making in some areas of medicine—especially in the end of life and palliative medicine domains—is clearly a positive development, as it provides room for dialogue in the process leading up to the expression of the decision, the outcome of which is then recorded in the form of consent. Further solutions could entail that patients can request for certain people to be adopted as full members of the clinical care team—as increasingly practiced in institutions practicing patient-centred care. Finally, protocols for decision making at the end of life, and in healthcare more generally, should include the consideration of aspects that are meaningful to those involved, rather than corresponding to a narrowly defined notion of rationality, safety, or clinical utility (I have referred to these as “social biomarkers,” Prainsack 2014; see also Gawande 2014; NHS Scotland 2016). Such a focus on personal meaning would shift the point of gravity of personalised medicine in such a way that it comes closer to patient-centred healthcare (Kitson et al. 2013).

In the field of live organ donations, we need to cease operating with the distinction between altruistic and non-altruistic donations in theory and in practice. This, in turn, would have consequences for how we think about “rewards” for donations: If we accept that living donations always include both self-interested other-regarding considerations on the side of the donor, then donors can be seen to accept certain risks

that come along with their donation, and to deserve some reward. Rewards typically take two main forms: financial rewards and in-kind rewards. Financial rewards as “payments”—namely those that go beyond compensation of income-loss and the reimbursement of actual expenses in case of living donations, but also tax credits for registered donors, or payments to families of deceased donors—have been criticized for many reasons. For example, they bear the risk of exploiting those in need of money, and of the commodification of human body parts (e.g. Adair & Wigmore 2011).

In-kind rewards give potential or actual donors or their family members prioritized access to donations. This can be organized on a relatively small scale, in so-called “donor clubs” such as *LifeSharers* (lifesharing.org), or on a national scale (Prainsack & Buyx 2017, Chapter 7). Examples of the latter are national systems of presumed consent in the context of cadaveric donations. It means that everybody is considered an organ donor unless they have explicitly opted out. When presumed consent operates in countries with trustworthy institutions, risks for individuals are very small, with the biggest risk being that somebody with a religious, spiritual or other important reason for not wanting to donate an organ was not aware of the opt-out requirement and donates an organ *post mortem*. While this risk can be avoided by making information on the opt-out requirement easily available, or by contacting the deceased person’s family to ascertain that she did not have such reservations, the benefits of such a system are considerable: A much greater availability of organs that makes the consideration of financial rewards unnecessary. The practice of free-riding—namely that those who opt out of the donor list would still be eligible to receive donations—has not proven to be an issue in countries that currently utilize presumed consent.

Furthermore, from a relational autonomy point of view, national systems of presumed consent are preferable to smaller club-models that reward individual patients or their families directly. This is the case because national presumed consent models realize indirect forms of reciprocity and rewards that accommodate—and aim to strengthen—people’s connections to others, and not only to their immediate family or another exclusive group.

Moving away from the distinction between “truly” altruistic vs. self-interested motivations for organ donation would have another advantage: It would foreground questions that emphasize relational and collective concerns—such as inequalities and mechanisms for access and inclusion. It would make us focus on what people have in common, and not what sets them apart, and increase the space for the discussion of meaning, rather than individual “choices” and motivations. If solidarity is understood, as we have suggested, as a practice expressing the commitment to accept “costs” to help others with whom we recognize similarity in a relevant respect, then this leads us to ask an even wider question that concerns the organization of healthcare as a whole: If persons are seen as relational beings whose boundaries are porous, can we isolate the benefit and wellbeing of some from the fate of others? If we conclude—as I suggest—that we cannot, would this not lead us to supporting universal healthcare that is accessible and affordable for all?

In connection with health data governance, the dominant Western understanding of people as bounded individuals is reflected in the failure of legal frameworks to protect the needs and interests of secondary data subjects (Widdows 2013; M. Taylor 2012). Moreover, in the present debate, the focus on atomistic individual autonomy has led

to efforts being channelled into increasing individual control over health data use at the cost of expanding collective ownership and oversight. If we want to start to counterbalance the growing power asymmetry between patients and citizens who give data, and large corporations who use them, then we need to also enhance collective ownership and control. Ways to do this include the strengthening of harm mitigation instruments to ensure that people who are harmed by data use have effective remedies—which the legal system does not always provide—as well as placing more emphasis on whether or not data use is in the public interest (Prainsack & Buyx 2016; Prainsack, forthcoming).

Conclusion: Solidarity in the era of personalized medicine

Three brief examples from different areas of medical practice have illustrated problems with the Western focus on independent and strategically rational individuals in different ways. The case of healthcare at the end of life highlights the problems posed by the assumption that decisions are regularly made by one person. In the case of live organ donations, the idea that people act either out of self-interest or out of care for others (“altruism”) has had a range of unintended consequences that are arguably best addressed by employing a system of presumed consent with very easy opt-out mechanisms for those who do not want to be part of such a solidaristic system. In the field of health data governance, I have argued that the social nature of data merits the explicit acknowledgement of the interests of secondary data subjects, as well as the strengthening of collective ownership and oversight over data infrastructures and data use. I have posited that a solidarity-based approach, which is underpinned by the conviction that all human practices are relational and thus both self-interested and other-oriented at the same time, can help us to move beyond an

understanding of individuals as self-interested, bounded entities. It can inform new frameworks that acknowledge and support people's connections to others. Moreover, a solidarity-based approach avoids the communitarian weakness of seeming to privilege the public good at the cost of the needs and interests of individual people. Solidarity-based frameworks start with what people need, want, and do, and, on the basis of this, seek to create the circumstances within which practices that support others can be more easily "scaled up" to become more widespread. Because of its grounding in actual practices and values solidarity is less vulnerable than other pro-social concepts to being used to justify pushing people into doing something they do not want to do for the sake of collective benefit (Prainsack & Buyx 2017; see also Howard 1995).^v Solidarity-based frameworks thus emphasize the simultaneous importance of personal and collective needs, interests and responsibilities, and focus action on the space where the two overlap.

In order to fill the concept of personalized medicine with new meaning that accommodates the relational nature of persons and prominently includes also aspects of people's lives that do not lend themselves to precise measurement and quantification, we need new ethical and regulatory instruments. These instruments need to leave behind old assumptions and categories that have proven unhelpful. The concept of solidarity can provide fruitful guidance in the design of these new instruments. A solidarity-based perspective means that we can expect that people who voluntarily decide to do something for others—may it be volunteering for a biobank, participating in decision making, or even donating an organ—accept some "costs" (again understood as any contribution of emotional, effort-wise, financial, or other nature). In such a model, people's contributions are best seen as gifts; they are given

voluntarily and their value cannot be captured in financial terms (see Zeiler 2014). At the same time, the meaning of a specific gift and the meaning of voluntariness are shaped also by the social relations and mutual obligations that the gift-giver and the recipient are part of. Whilst a giver of a gift does not—or at least should not—expect payment or another form of direct compensation for the gift, there is always, as Bob Simpson put it, a “web of indebtedness and future reciprocity that the “gift” creates once put into circulation” (Simpson 2014: 342).

What is the substantive content of this debt, this reciprocity that the gift articulates (besides all the other things that it does)? Given that donors to a biobank, volunteers in a hospital, or donors of an organ are typically not part of a physical community that shares their values and day-to-day lives with the recipients of their gifts, it is in practice often difficult to establish what the standards are that shape the content of reciprocal relations and commitments. However, what the gift-giver should be able to expect from the recipient is that she will be treated according to the same standards that she herself accords the recipient(s). This is why a solidaristic perspective mandates that we work towards achieving greater symmetry and reciprocity between people within the institutional and organizational context in which the “gift” is given. In the context of medicine, this would mean that people are told openly what goals and purposes the recipients of their gifts work towards. They should also be able to learn about the values and purposes underpinning the group or organization receiving the gift. Greater reciprocity would also mean that people can bring their own meanings and concerns to the table. They should also be included in what we consider the “tapestry of potentially high-value information sources” (Weber et al. 2014). At a

moment where most patients are also data donors for research, such a development would be more than timely.

Another one of the key implications of a solidarity-based approach to healthcare in the era of personalized medicine is a focus on universal healthcare. I have argued that by understanding humans as relational creatures whose wellbeing depends on the wellbeing of others, it is not possible to draw a clear line between self-interested and other-directed practice. But neither is it possible to completely separate the fulfilment of needs and interests of any given person from the fulfilment of needs and interests of others. Meeting the fundamental needs of all people as well as possible is thus both a personal and a collective interest and responsibility. Given that health is one of the fundamental—if not *the* fundamental—needs of human beings, universal and affordable healthcare should be the precondition for any other pursuit in medicine. It certainly is a precondition for the realization of personalized medicine. Such an emphasis on universal healthcare, emerging out of the solidarity-based approach, thus does not require an individually enforceable right to health, which would run the risk that those who are already privileged are more active or effective in enforcing their rights than others. It is a shared interest and responsibility.

Having said this, the relational understanding of personhood underpinning the solidarity-based approach is not without implications for our understanding of human rights. It affects how we understand the “human” in human rights (see Benedict Douglas’s contribution to this Special Issue; Douglas 2018). An atomistic understanding of personhood has shaped how human rights have been conceived and enacted for centuries: It is the idea of protecting the agency and interests of

individuals that the very idea of human rights hinges upon, rendering “humans” and “individuals” synonymous.

Replacing the old Western understanding of the independent individual as the structuring principle of our social and political space with a relational understanding of personhood does not mean that we stop recognizing the autonomy of people. As argued in this paper, especially where people’s physical integrity is at stake, there will always be the need to foreground the agency and decision-making power of the people in and with these bodies. But as in the domain of human rights, there are clear examples of how social relations and collective meaning are already shaping the meaning of individual rights. The freedom of religion, the right to family life, and the freedom from racial or sexual discrimination are all protected as subjective *individual* rights in human rights frameworks. At the same time, they obtain their meaning through characteristics that emerge in the context of groups and communities, not individual people; individuals may not even consider themselves to possess the trait on the basis of which they experience discrimination (e.g. a person with an exotic and “foreign” sounding name that leads to discrimination when applying for jobs, although this person does not identify with the group she is seen to belong to). In response to this article, Simpson (see Bob Simpson’s contribution to this Special Issue; Simpson 2018) makes a case for a “duplex nature of personhood.” This approach can guide our way here. In addition to protecting the person with and in the body whose integrity is at stake (i.e. protecting rights of *individuals*), as argued above, human rights could also protect persons as part of their human, natural and artifactual environments. This, in turn, would mean that the needs and interests of human and nonhuman environments of people take a more central role in the interpretation of

individual rights. Not to overrule a person's needs and interests, but to strengthen the area where personal and collective needs and interests coincide.

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ⁱ See also Simpson’s discussion of Lambek’s notion of the “forensic person” who he traces back to John Locke’s treatment of persons as, in Simpson’s words, “temporally continuous and rationally accountable” (Simpson 2018, this Special Issue). Lambek contrasts the forensic person with the “mimetic person,” which “highlight[s] temporal discontinuity and difference within the person, acknowledging that we are not always fully whole, single, consistent, or sealed off from those around us” (Lambek 2013: 852).

ⁱⁱ I borrow this headline from the title of Monika Schreiber’s (2014) book *The comfort of kin: Samaritan community, kinship, and marriage*.

ⁱⁱⁱ Data were taken from the irodat.com database, which offers continuously updated information on organ donation from many countries around the world.

^{iv} In forensic identification, for example, DNA information is sometimes used exactly for this purpose (e.g. “familial searching”; see Kaye 2013).

^v An exception is when solidaristic arrangements are realized by legal, administrative or bureaucratic norms; Alena Buyx and I call it “tier 3” solidarity, which is the most institutionalized form of solidarity after interpersonal solidarity (tier 1), and group-based/communal solidarity (tier 2). Although strictly speaking solidarity realized by legal norms—such as progressive taxation—does not require to be underpinned by actual solidaristic practice by people to be enforceable, it will be much more effective if it corresponds with what people want to do and are actually doing.